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Parents' needs for physician-parent communication in the face of life-threatening illness: qualitative analysis

Abstract

Introduction. Parents of a child diagnosed with a life-threatening illness often experience the state of cognitive and emotional disorganization. The key factor determining parents-physicians cooperation is the quality of their relations. That is why physicians should be familiar with conditions that may help or disturb parents to manage this extreme situation. Competent communication leads to more effective treatment as well as fewer medical malpractice claims and lawsuits filed against doctors.

Material and methods. The aim of this paper is the description and analysis of the needs of 23 parents whose children were diagnosed with life-threatening illnesses that led to death. The deceased children were treated mainly in hospitals or in hospices. The study was conducted in the period of one up to four years following the death of a child. A semi-structured interview was constructed and used for the purpose of this research. The transcription was analysed according to the rules of Qualitative Content Analysis with applying NVivo 9 software.

Results. The results have revealed five categories of parents' needs addressed to physicians: 1) a greater intensity of direct parent-physician contact; 2) experience of doctors' thorough knowledge about the child and their illness; 3) a greater doctors' involvement in the search for the causes of the disease and further treatment; 4) parents' established position in the healthcare system, especially when the treatment lasted for a long time 5) more clear information about the applied treatment and condition of the child.

Conclusions. The research indicates that the challenge of communication with parents is not only clear information about the course of a disease, providing facts about functioning of the entire health care system and this is particularly important for the parents whose child has been undergoing a long-term treatment. A physician should emphasise the meaning of palliative care as an integrated system of support. Parents' decision-making about medical treatment on the early stage of an illness may cause too heavy strain to some of them.

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Key words: life-threatening illness, health communication; family, parents-physicians; patients, psycho-oncology

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Introduction

The results of research present that up to 1/3 of patients complaints is related to various aspects of insufficient communication with physicians [1]. The key factor determining parents-physicians cooperation is the quality of their relations [2, 3]. More and more often patients expect health care staff to have psychological and interpersonal competencies such as empathy, openness and kindness. Moreover, for many patients, physician's behaviour has as great importance as their qualifications. Psychological competencies of medical staff are frequently discussed and physicians use them as an applicable tool in their practice. There are differences between physicians who are sued more often than their colleagues. It appears that they spend less time with their patients, less frequently inform them about the planned treatment and are not as much involved in active listening. There is no difference between the amount and quality of information given to patients by the doctors who have been sued and those who have not. The doctors with fewer lawsuits do not provide more details about their patients' health condition than those who have been sued. The basic difference is the way they communicate with others [4].

Parents of a child diagnosed with a life-threatening illness are a special group displaying unpredictable behaviours and excessive anxiety. On the early stage, their anxiety may be related to diagnosis, and then to prognosis. This feeling rises in initially strange hospital environment and results in decreasing sense of parental competences in taking care of their ill child [5]. The conducted research has found that a child's serious illness causes their parents' cognitive and emotional disorganization [6]. Moreover, in the above described situation, related to an illness and applied treatment, the parents should obtain honest and complete information indispensable for raising trust and belief that the doctors do their best to save their child's life. They should be certain that even if it is not possible, their child will receive the best symptom-related treatment [7].

Children diagnosed with cancer who undergo palliative care, usually live shorter than those suffering from other long-term and life-threatening diseases. Some research suggests that it is especially important to their parents to perceive palliative care as an integrated system of relieving the suffering of patients [8]. This is usually connected with acknowledging the limitation of cancer treatment. The parents should also participate in the care of their child [9, 10].

Parents of the children diagnosed with a life-threatening illness often claim that their above named needs are not satisfied. This is the reason why medical

staff should become more aware of the behaviours that in parents opinions, helped or disturbed when they had to face a stressful situation. Studies carried out by Cacciatore and her colleagues reveal opposing dimensions that determine attitudes defined by parents, i.e.: engagement and warmth in contrast to objectification and emotional detachment. Consequently, honesty and disclosure are in contrast to withholding information resulting in misrepresentations as well as objectification and partnership are in contradiction with paternalism and coercion. Flexibility and individualized care are in contrast with inflexibility and rule-bound uniformity [11].

Individualized care is especially valued in the face of the approaching death of a child. Parents should be provided with their own place while staying in the hospital ward and they should be personally involved in the care of their child [2]. This kind of ongoing interest displayed by medical staff is thought to be a key factor for preserving parental positive recollections of the last period of being with their child. Similarly, what seems to be priceless for parents when their child is dying, is the time spent together and the space in which they can have some intimacy, also after the child's death [12]. The above studies show three basic aspects of relations between medical staff and parents. The open and honest communication, tailored to the parents' abilities, related to diagnosis, prognosis and treatment as well as to functioning of medical care is considered as the most important one. The second aspect means familiarizing parents with goals behind the successive phases of the applied therapy. It is easier to engage parents in the process of care and to enable them to stay close to the child when these two aspects are fulfilled. The third, and probably the most difficult aspect indicates the need of emotional, individualized approach to the child and their parents. It is worth mentioning that the needs of parents whose child suffers from cancer may vary significantly due to the dynamic changes in the course of illness. The situation of parents whose child is diagnosed with a life-threatening illness is highly stressful. The parents must face dynamic changes resulting from progressing illness. What is more, first months following the death are considered to be the period of the most severe grief related to separation and traumatic stress.

Material and methods

Aim of the study

The aim of this study is the description and analysis of parental needs directed towards physicians during hospitalization of a child diagnosed with a life-threatening illness.

Participants

The research group consisted of the parents of deceased children — 10 married couples and 3 mothers (N = 23). As it has been mentioned above, the situation of a child diagnosed with a life-threatening illness is characterized by a high level of stress as well as the changing situation of the child. The first months following the death are considered to be the period of the most severe grief related to separation and traumatic stress. For this reason, the parents were examined at least one year after the death of the child. Thus, parents' needs directed to the physicians were formulated retrospectively. This moment of data collection allowed gathering opinions which are just more like a summary and are not formulated under the influence of currently experienced extreme stress.

The past few months before the child's death, the parents and their child were under the care of children's hospices. Parents' opinions relate to the whole

course of their child's illness who also was treated in other medical institutions in Poland.

Table 1 presents the study group of parents whose child was diagnosed with a life-threatening illness. Due to its character, they were in constant long-term contact with physicians (on average for 24 months). In the group of 7 children who suffered from cancer, the treatment lasted from 6 months to 3 years. In the other group of 8 children the time of their illness varied from 4 to 7 years.

A criterion for including parents in the research group was their child's death caused by an illness within 1 to 4 years. The parents who were taking care of their child during the illness and treatment were also included in the research group. Those parents whose child's death was caused by an accident or suicide, as well as those who visited doctors due to their own psychopathological disorders or a somatic, chronic disease, were excluded from the research group (see Table 1).

Table 1. Study group of parents and their children

Parents' age, education	Child's age Diagnosis	Duration of illness Applied treatment
1. Mother, 50, secondary education father, 55, vocational education	Girl 17, cerebellum cancer	3 years, 3 surgeries, radiotherapy, chemotherapy, metastases
2. Mother, 35, university education father, 40, secondary education	Girl 7, genetic disease: glycogenosis type 4	7 years, liver transplantation, physical rehabilitation, inflammatory conditions, immunosuppressive treatment, septic shock, multiorgan failure
3. Mother, 44, secondary education	Boy 17, malignant bone tumour Ewing sarcoma, Sacroiliac tumour	3 years, iliac crest surgery, radiotherapy, che- motherapy, physical rehabilitation,
4. Mother, 40, university education father, 42, university education	Girl 6, brain cancer, glioma grade 4	1 year, brain cancer surgery, chemotherapy
5. Mother, 35, secondary education	Girl 7, glioma of the brainstem	1 year, chemotherapy
6 and 7. Mother, 32, secondary education father, 34, secondary education	Boy 4 m.o., girl 6.5 m.o., genetic disease: Zelweger Syn- drome	10 years 5 months, hospital treatment, brain and organs mal- functions
8. Mother, 30, secondary education father, 30, secondary education	Boy 2, cerebral palsy, severe perinatal hypoxia	2 years (including 10 months of hospital treatment), organ failure
9. Mother, 38, university education father, 40, secondary education	Boy 8, Idiopathic nephrotic syndrome	4 years (including 2 years of dialysis), transplantation of the kidney, respiratory failure
10. Mother, 33, university education father, 35, university education	Boy 3.5, genetic disease: Alpers Syndrome	2 years, brain and liver failure, outpatient and hospital treatment,
11. Mother, 30, university education father, 34, university education	Girl 8 m.o., nephrotic syndrome	4 months of hospital treatment, inflammatory conditions



Table 1 (cont.). Study group of parents and their children

Parents' age, education	Child's age Diagnosis	Duration of illness Applied treatment
12. Mother, 30, university education father, 32, university education	Boy 2, glioma	13 months in hospital, chemotherapy
13. Mother, 36, university education	Boy 10 m.o., genetic disease: mitochondrial cytopathy	10 months of outpatient and hospital treatment
14. Mother, 30, secondary education father, 35, university education	Boy 2.5, brain cancer: glioma grade 4	6 months in hospital, brain tumour surgery, chemotherapy

The hospice staff asked the parents of the deceased child to take part in the study following 1 up to 4 years following the death. A semi-structured interview was constructed and used for the purpose of this research. The questions concerned the feelings and emotions the parents experienced both before and after the death of their child. They were interviewed in their places and the time convenient to them. Their answers were audio-recorded and then the transcript was made.

The study is a part of the project named "Factors Conditioning Persistent and Prolonged Grief and Its Impact on Functioning Family Members", which was approved by Bioethics Committee of Collegium Medicum at Jagiellonian University (KBET/149/B/2013 of 6 June, 2013).

The presented results relate to the answers given to one of the interview questions: *"What did you need from the physicians/medical staff starting from the time of diagnosis to the child's death?"* [the complete interview enclosed].

Transcripts of the parents responses to the above question was analysed Qualitative Content Analysis [13]. Because the goal of this study was to present direct parents' opinions on their relations with physicians, we chose such a type of data analysis in which a direct content of verbal opinions was categorized in contrast to categorizing their veiled message or interpreted by the researcher [14].

When it comes to specifying medical and psychological consequences of the identified categories, the analytical data interpretation was much deeper as we related to both: the content of the given opinion as well as to the way of its construction: emotional saturation, understatements etc. The analysis, carried out with the use of NVivo 9 — QSR International software, was based on the open coding of the transcript,

which means that separate pieces of verbal opinions were categorized according to their meanings. i.e.: *"the courage of directly confessing to professional incompetence"*. This type of coding allowed to define subcategories that were next grouped in line with the similarities of communication processes and their consequences. Then, they were placed in the five main categories (see Table 2).

Results

On the basis of the Qualitative Content Analysis the five main categories were identified. They name and define parents' needs in the face of their child's illness.

These categories differ in the frequency of occurrence in the examined transcripts:

1. *The need for a direct contact with a physician — availability and co-operation* not only appeared most frequently in the narrations of the interviewed parents (N = 23), but they were also included in the main category which describes the process of direct, favourable co-operation in parents-physician communication. Other physicians' behaviours named by parents, and indispensable for such co-operation are described by four other main categories:
2. *The need for being recognized as an individual.*
3. *The importance of physicians' commitment and conveying this attitude to the parents.*
4. *The acknowledged position of parents in the treatment system.*
5. *The need for understanding treatment and functioning of health care system.*

As we mentioned above, these categories directly relate to the basic groups of parents' needs established in line with grouping more specified needs included in subcategories (Table 2, column 1).

Table 2. Basic categories according to parents' opinions on their needs related to their child's illness and treatment

Name of need, the number of categories related to the child's illness	Category definition	Source of opinion
1. The need for a direct contact with a physician-availability and co-operation N = 8:37 Subcategories: — direct, favourable co-operation in parents-physician communication related to the symptoms of the illness in the child N = 6:19 — "a technical-procedural approach" as making communication related to the symptoms impossible N = 3:10 — indirect perception of anxiety in medical staff N = 5:8	In the positive version this category describes favourable, permanent contact with physicians related to the improvement of the child's health. In the negative aspect it focuses on the chaos in the treatment and parents' anxiety. Consequences of the satisfied need: A direct contact (phone call) in the case of any changes in the child's health condition. Parents' attention focused on the mechanisms of the illness and its treatment; the sense of safety related to doctor's accessibility and cooperation. Consequences of the unsatisfied need: Certain ambiguity as to the plan of treatment, anxiety, distrust.	<i>"I wasn't afraid of talking to the doctor at all, I did not feel their superiority, I did not feel such...I could ask any, even silly questions. I was that everything is ok. that his oesophagus was unobstructed and he obtained 8 points, so his condition was very good; he was referred to the intensive therapy to recover in the incubator. But the very next day he had 10.000 small pipes, drips in his body and his respiratory system was supported. Nobody told us then but we learned out from the documentation that he was reanimated the first. Nobody laughed at me or made strange faces. We were there (oncology ward) four times" — (mother whose son suffered from cancer).</i> <i>They told me that everything was ok., that they checked there was no gastrointestinal night.(father of a child diagnosed with cerebral palsy)</i> The contact with doctors at The Children's Memorial Health Institute was not good. We could phone our doctors any time if the day or night but in the Institute nobody could say anything; when we talked to the doctor on duty, he did not know what to do either. (mother of a child diagnosed with kidney disease).
2. The need for being recognized as an individual N = 9:27 Subcategories: — the importance of satisfying other needs rather than treatment — "a technical-procedural approach" as making communication related to the symptoms impossible N = 3:10 — the meaning of displaying interest not only in the illness but also in the child N = 3:6 — the need of accessibility to physician's emotions N = 4:6 — appreciation of procedures allowing to say good bye to the deceased child N = 3:5	This need relates both to the professional approach towards the ill child and interpersonal skills. Consequences of the satisfied need: Parents' awareness of the possibilities of further treatment. Recognizing a child as an individual being raises a sense of uniqueness and that is especially important in the advanced phases of illness. Consequences of the unsatisfied need: The sense of anonymity and doubts related to the further treatment.	<i>I was a good luck in this unhappy situation that our daughter was under the care of the doctor who treated our son. He remembered us perfectly although five years passed; he said that when he heard about the syndrome and our name, he was sure it concerned us. He remembered us perfectly... (father of children suffering from a genetic disease).</i> <i>"...her first question was about the date of our son's birthday. I was simply stunned...My God — I thought to myself- how much caring she must be, how much interested in the child to ask the question about my son's birthday. (mother of a child diagnosed with cancer)</i> <i>„...so we were not admitted to the nephrology ward in the Institute but to paediatrics ward and we stayed in an isolation room. So I think whether we received the proper care in paediatrics ward, whether everything was in order if it was not the nephrology ward. (mother of a child diagnosed with kidney disease).</i>



Table 2 (cont.). Basic categories according to parents' opinions on their needs related to their child's illness and treatment

Name of need, the number of categories related to the child's illness	Category definition	Source of opinion
3. The importance of physicians' commitment and conveying his attitude to the parents N = 7:16 Subcategories: — the importance of attention and accuracy N = 6:11 — the courage of directly confessing to professional incompetence N = 4:5	This category relates to the need of experiencing physicians' commitment and effective communication with parents, including the reasons for ambiguity. Consequences of the satisfied need: Understanding and accepting difficult medical information and impossibility of further treatment. Consequences of the unsatisfied need of involvement related to blurred and inaccurate information raises veiled anger and questions physicians' professional competences.	<i>"and the doctor herself... I will be probably grateful to her to the end of my life. I even thought that I should find her somewhere, but I even do not know her name ... she is a young girl... I am grateful that she did not piss us off" (mother of a child diagnosed with cancer).</i> <i>"Yes...and the doctor...I came in and he was so calm. No, ... first, I was angry...Today, I see it differently...He took out such a film, frame after frame our daughter's brain....He said the symptoms appeared due to the brain tumour and we would go to the Institute." (mother of a child diagnosed with cancer)</i> <i>"Yes, he started telling me something in his way and told me that we would meet probably the next day in the afternoon or something like that. But he did not tell us anything particular,... he said that they would have to insert the valve soon and he had to perform biopsy... and see. What else did he say? Not about the surgery, but he said he was afraid of performing that biopsy." (father of a child diagnosed with genetic disease)</i>
4. The acknowledged position of parents in the treatment system N = 8:21 cancer, 6 other illnesses Subcategories: — using the parents' knowledge acquired in the course of illness N = 3:7 — experiencing lack of information about the child's health condition N = 4:11 — the need of taking control by a physician in the case of parents' helplessness N = 3:4	This category especially relates to the situation of a long-time illness. The parents indicated the need of being involved in the treatment. Consequences of the satisfied need: a regular observation of the child, the sense of competence and impact on the course of events. Consequences of the unsatisfied need: distrust and anxiety about the effectiveness of applied treatment. The parents of children suffering from cancer of dynamic character declared the need for taking decisions on their behalf.	<i>"Here, in Sosnowiec, the doctor who performed the surgery said that we were his link with Warsaw where from we obtained information on the medication. He listened to us as he trusted us, and believed that we called the professor from Warsaw regularly and she told us what medication should be administered and what doses should be given, so the doctor took up the therapy. (mother of a child diagnosed with genetic disease).</i> <i>"We did not want to more clever than the doctors. I only asked for the contact with Warsaw to consult them as they had the knowledge. The head of the hospital ward did not have any knowledge about transplantation. The most painful was the fact that she neither listened to us nor to other parents. There were dramatic arguments there. (father of a child diagnosed with genetic disease).</i> <i>"There is something wrong in the system. The professor told us that we could choose the clinic but how we could know what to choose" (mother of a child diagnosed with cancer).</i>
5. The need for understanding treatment and functioning of health care system N = 5:18 Subcategories: — concealing, withholding information as a source of anxiety and distrust N = 4:12 — the courage of directly confessing to professional incompetence N = 5:6	This category relates to the opinions in which parents complained about not being properly informed about the child's condition and the course of treatment. At the same time, they wanted to be involved and aware of the range of uncertainty in the very moment of the treatment. Consequences of the satisfied need: The sense of togetherness and exchange of information with other parents of the children suffering from similar illnesses; appreciation of physicians' efforts. Consequences of the unsatisfied need: growing distrust of the course of treatment as well as towards physicians and the system.	<i>"He was the first doctor who was brave enough to talk to us and to tell us that they didn't know what was going on with our son, what illness it was. He informed us that there was an illness that had been described and known as Leigh syndrome and its symptoms were very much alike they observed in our son. Next, we got in touch with the parents whose children suffered from Leigh syndrome.</i> <i>It seemed that the nephrologists consulted the case, at least the doctors said so..., I am not sure... we had not experienced such a situation before, we did not know how to start, what we should have been given from the hospital. Me and my daughter were placed in an isolation room in the paediatrics ward, the medication did not work, her body was more and more swollen, less and less fluids were lost from the body.</i> <i>The doctors seemed not to say anything about her critical condition, anything that we should have been ready for the worst (mother of a child diagnosed with liver disease).</i>

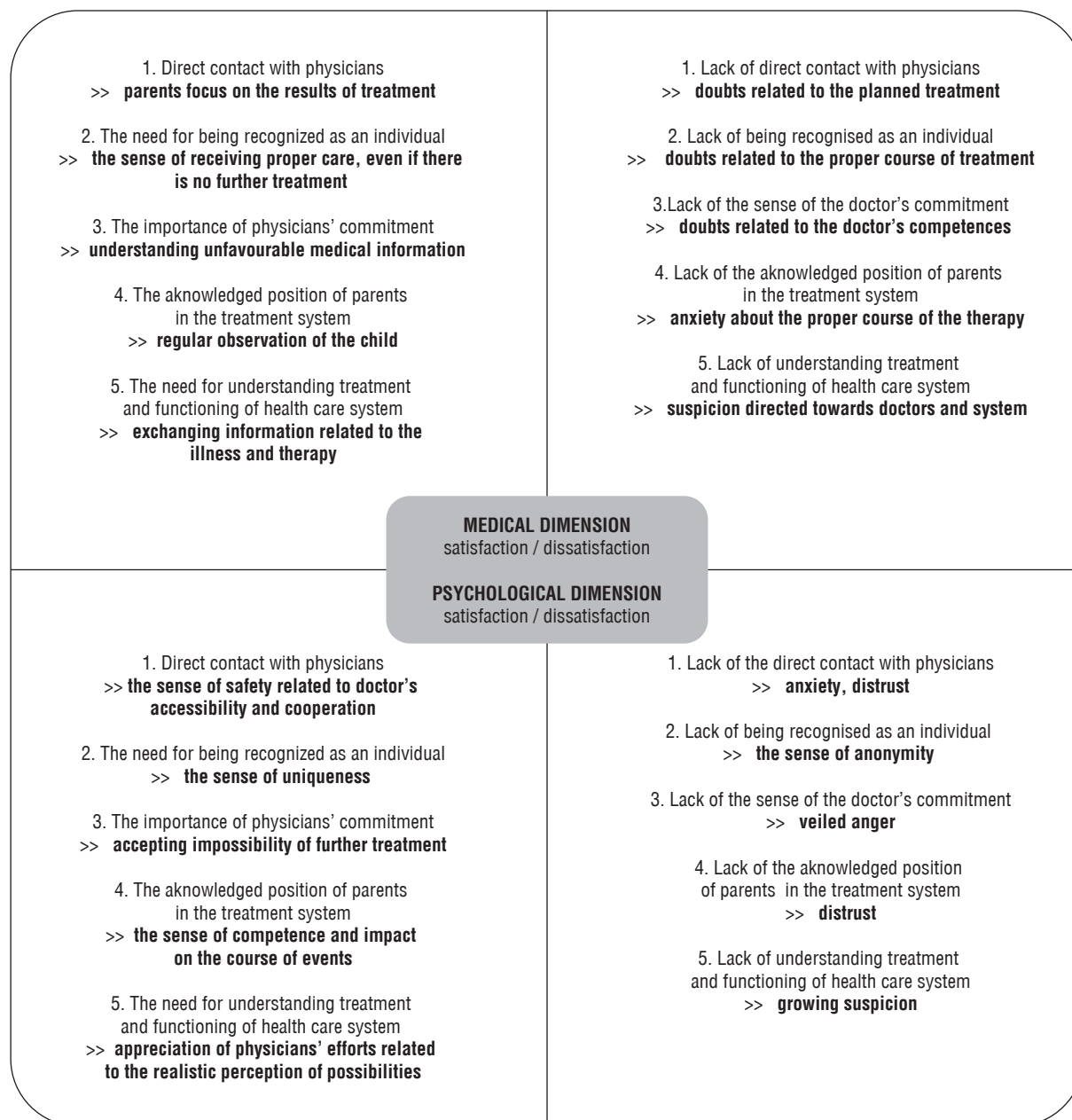


Figure 1. Parents perception related to medical and psychological consequences of satisfying their needs

A significant result of the analysis is the fact that the consequences of satisfied and unsatisfied parents' needs are represented by 5 categories (Table 2) belong to two connected dimensions: medical-directly influencing parents' cooperation in the treatment process and psychological related to a parent's internal condition (see Figure 1).

Discussion

The study confirmed the significance of receiving honest and complete information which was postulated by the researchers [5, 11]. Moreover, it highlighted the

necessity of keeping parents informed of their child's health condition in contrast to familiarizing them only with some elements of diagnosis. The postulated physician's commitment to rescuing the child's life was also appreciated by the interviewed parents [7]. The analysis not only shows their need for understanding the mechanisms of the illness and treatment but also the need of being introduced into functioning of the healthcare system. Some consequences of direct physician-parent communication, such as focusing on treatment methods, understanding unfavourable medical information, regular observation of the child and exchanging information with a doctor are crucial for obtaining desirable effects

of causal treatment and reducing symptoms of the illness in the child. The medical consequences of unsatisfying the above needs have ranged from ambiguity and doubts about medical procedures to scepticism and distrustfulness related to the applied treatment.

The analysis of parents' opinions indicates the meaning of establishing emotional contacts and interpersonal relationship both with the parents and their child. The researchers postulated direct contact which was in contrast to "a technical-procedural approach" and recognizing both the parents and their child as individuals versus frequent anonymity. (e.g.: *"I wasn't afraid of talking to the doctor at all, I did not feel their superiority, I did not feel such...I could ask any, even silly questions"; "Doctor remembered us perfectly although five years passed...."*).

Presented research has indicated that such attitudes of medical staff resulted in the sense of being under widely understood care and reducing symptoms of the illness, even if there is no further treatment or cure for the illness.

The psychological consequences of satisfying the above needs have been related to decreasing parents' anxiety described in the previous research as emotional and cognitive "disorganization", permanently experienced by parents [5, 6]. This study only partly confirms conclusions drawn from the results of other research concerning the importance of being included in the system providing proper health care to the child [10]. In this case, it was mainly the need of those parents whose children suffered from a long-term illness. On the early stage of an illness, including parents into decision-making about medical treatment imposed heavy psychological strain on them.

Interpreting the results regarding *"the need for being recognized as an individual"*, we should take into account that a physician's personal interest in a child, not only in the illness itself, may lay particular burden on them as it incurs considerable risk of experiencing the acute sense of loss following the child's death. On the other hand, taking care of a parent's emotional condition means at the same time proper clinical care of a treated-child. As-usually one of the parents spends most time with their ill child and his or her emotional state influences directly the child's frame of mind.

Proposed clinical recommendations

The study indicates that the understandable way of transmitting information about the illness, recommended-treatment, and functioning health care system is a substantial thing for the parents whose child is diagnosed with a life-threatening illness. The latter is

especially significant, for parents whose child suffers from a long-term illness.

However, at the beginning of an illness, the doctors should rather provide the plan of treatment that is as clear and concrete as possible. The continuity of regarding child's clinical condition seems to be the matter of importance as it can help to diminish recurrent parental doubts and anxieties. The key communicational facet is also bidirectional exchange of information that relays on the physician's interest in parental current assessment of child's condition.

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Enclosure

Semi-structured interview "The illness and death of a child"

1. Could you tell me about your child?
2. Could you describe the first stages of your contact with medical staff in relation to diagnosis? How was your child's illness diagnosed?
3. How was the information about the illness given to you? How did you respond to it? Was the information understandable to you?
4. What was the further treatment like? What was the most difficult to you? Are there any positive

memories (concerning contacts with your child, family events, relations with medical staff or other people)?

5. Do you remember that moment when you realised your child was terminally ill? When did it happen? Could you describe that situation?
6. How do you remember the time when your child was dying? Are you able to tell me what was happening then?
7. With the perspective time gives, are you able to tell what you needed from physicians/medical staff from the very beginning of the illness until your child's death?